

We are carrying out a study to investigate the awareness and opinions of pregnant women about tests that screen for Down Syndrome and other fetal anomalies.

We greatly appreciate if you could take a few minutes to complete this short anonymous questionnaire. Thank you.

The first section is about you.

Please complete the following questions. Tick one.

What is your age? _____

What is your ethnicity?

- | | |
|--|---|
| <input type="checkbox"/> Irish | <input type="checkbox"/> African |
| <input type="checkbox"/> Irish Traveller | <input type="checkbox"/> Any other Black background |
| <input type="checkbox"/> Other White | <input type="checkbox"/> Asian |
| <input type="checkbox"/> Mixed Ethnicity | <input type="checkbox"/> Other _____ |

How many children do you have?

- | | | |
|--|---|--|
| <input type="checkbox"/> First pregnancy | <input type="checkbox"/> Two children already | <input type="checkbox"/> Four or more children already |
| <input type="checkbox"/> One child already | <input type="checkbox"/> Three children already | |

Have you had a previous miscarriage or pregnancy loss?

- | | |
|------------------------------|-----------------------------|
| <input type="checkbox"/> Yes | <input type="checkbox"/> No |
|------------------------------|-----------------------------|

What is your highest education level?

- | | |
|---|---|
| <input type="checkbox"/> Primary school | <input type="checkbox"/> Third level education (University/College) |
| <input type="checkbox"/> Secondary school | <input type="checkbox"/> Postgraduate education (Masters/PhD) |

Which type of clinic are you attending?

- | | |
|---------------------------------|----------------------------------|
| <input type="checkbox"/> Public | <input type="checkbox"/> Private |
|---------------------------------|----------------------------------|

Which type of clinician is taking care of your pregnancy?

- | | | |
|----------------------------------|--|---|
| <input type="checkbox"/> Midwife | <input type="checkbox"/> Consultant/Registrar (Hospital) | <input type="checkbox"/> Consultant/Registrar (Private) |
|----------------------------------|--|---|

The next section is about screening tests for Down Syndrome.

Please complete the following questions. Tick all that you think apply.

What do you understand by 'screening for fetal anomalies'?

- Blood tests to look at the baby's DNA for risk of Down syndrome
- Blood tests to look at levels in the mother's blood.
- Ultrasound scan to look for signs of Down syndrome
- Measuring fluid on back of baby's neck
- Anatomy scan (also called "20-week scan" or "detailed scan" or "the big scan")
- Unsure

Where do you go to find information about screening tests for fetal anomalies?

- | | |
|-----------------------------------|---|
| <input type="checkbox"/> GP | <input type="checkbox"/> Obstetrician |
| <input type="checkbox"/> Friends | <input type="checkbox"/> Midwife at antenatal clinic |
| <input type="checkbox"/> Family | <input type="checkbox"/> I have never researched Prenatal Screening |
| <input type="checkbox"/> Internet | <input type="checkbox"/> Other _____ |

This next section is about the availability the screening tests.

Please complete the following questions. Tick one.

I believe all women should be routinely offered a prenatal screening test, regardless of age.

- | | | |
|--------------------------------|-----------------------------------|---------------------------------|
| <input type="checkbox"/> Agree | <input type="checkbox"/> Disagree | <input type="checkbox"/> Unsure |
|--------------------------------|-----------------------------------|---------------------------------|

I believe only women over the age of 35 should be routinely offered a prenatal screening test.

- | | | |
|--------------------------------|-----------------------------------|---------------------------------|
| <input type="checkbox"/> Agree | <input type="checkbox"/> Disagree | <input type="checkbox"/> Unsure |
|--------------------------------|-----------------------------------|---------------------------------|

Prenatal Screening can detect all babies with a disease or disability.

- Agree Disagree Unsure

The next section is about Down syndrome.

Please complete the following questions. Tick one.

How many babies are born with Down syndrome in Ireland per year?

- 1 in 70,000 1 in 70
 1 in 7,000 1 in 7
 1 in 700 Unsure

Prenatal Screening can detect all babies with Down syndrome.

- True False Unsure

Most Down syndrome babies are born to women over 35 years of age.

- True False Unsure

Which of the following factors increase a woman's likelihood of having a baby with Down syndrome? *Tick all that apply.*

- Increased age of mother Other family members with Down syndrome
 Increased age of father Other family members with autism
 Previous child with Down syndrome No folic acid supplementation during pregnancy
 Previous miscarriage Unsure

What do you think is your own personal risk of having a Down syndrome baby?

- Non-existent High
 Low Quite high
 Moderate Unsure

This next section is about your views on screening in early pregnancy to detect Down Syndrome.

Please complete the following questions. Tick all that apply.

If you were offered screening to test for Down Syndrome would you accept it?

- Yes No
 Yes, and I had this test in this pregnancy Not for Down Syndrome, but I would have screening tests for other fetal anomalies
 Undecided

If you would choose screening, why?

- To help make the decision to have a diagnostic test like amniocentesis
 I believe that I am at a higher risk for having a baby with Down Syndrome
 In order to check if my baby is healthy
 To allow my obstetrician to care for me with all the information
 I want to consider termination of pregnancy
 To allow everyone to better prepare before the baby is born if affected by Down syndrome
 To allow everyone to better prepare for another fetal anomaly
 Other _____

If you would not choose screening, why not?

- Not necessary – my personal risk is too low
 I am not sure how to get the test
 I think the screening test is inaccurate
 I am worried about what to do if the baby is affected
 I do not want to consider termination of pregnancy
 Potential cost of screening test
 Media reports about inaccuracy of screening
 Amniocentesis test needed for diagnosis after screening has too high a risk of miscarriage
 Other _____

The next section is about your perception of risk.

Please complete the following questions. Tick one.

Screening tests report the risk of Down syndrome in your baby (1 in 200 for example). At a certain level, the woman is said to be “high risk,” and may be offered a follow up diagnostic test. What level do you think is “high risk”?

- | | | | |
|----------------------------------|-------------------------------------|---------------------------------------|---------------------------------------|
| <input type="checkbox"/> 1 in 2 | <input type="checkbox"/> 1 in 100 | <input type="checkbox"/> 1 in 10,000 | <input type="checkbox"/> 1 in 200,000 |
| <input type="checkbox"/> 1 in 10 | <input type="checkbox"/> 1 in 1,000 | <input type="checkbox"/> 1 in 100,000 | <input type="checkbox"/> Unsure |

What does a low risk screening test result for Down Syndrome mean?

- My baby definitely does not have Down Syndrome
- My baby is less likely to have Down Syndrome
- My baby is more likely to have Down Syndrome
- My baby definitely does have Down Syndrome
- Unsure

What does a high risk screening test result for Down Syndrome mean?

- My baby definitely does not have Down Syndrome
- My baby is less likely to have Down Syndrome
- My baby is more likely to have Down Syndrome
- My baby definitely does have Down Syndrome
- Unsure

Women who receive an ‘*increased risk*’ result from a screening test may choose to undergo further tests that give a definite “yes or no” answer about conditions like Down syndrome. For example, women may choose to undergo an amniocentesis, where a very fine needle is directed through the mother’s abdomen into the womb, and a sample of amniotic fluid is taken. However, this carries a 1 in 200 risk of miscarriage.

- I would never undergo an amniocentesis test no matter what the screening test indicated about my personal risk result.
- I would always undergo an amniocentesis test no matter what the screening test indicated about my personal risk result.
- I would prefer a diagnostic test like an amniocentesis test rather than a screening test.
- I am not sure if I would undergo amniocentesis

The next section is about pregnancy termination.

Please complete the following questions. Tick all that apply.

My views on termination for my own pregnancies are:

- I would never terminate a pregnancy.
- I would only terminate a pregnancy if my health was at risk.
- I am unsure about terminating a pregnancy.
- I would terminate a pregnancy only because of a fatal fetal anomaly.
- I am not opposed to terminating a pregnancy.

In Ireland, women can choose to terminate their pregnancy before 12 weeks. Termination after 12 weeks is only allowed if a fatal fetal anomaly is diagnosed. Which of the following do you think are classified as fatal fetal anomalies?

- Anencephaly (a neural tube defect that causes abnormal development of the brain)
- Edwards Syndrome (Trisomy 18)
- Down Syndrome (Trisomy 21)
- Spina Bifida (a neural tube defect which causes incomplete development of the spinal cord)

Prenatal screening tests only report on the *risk* of the baby having Down Syndrome or another condition. If the screening result shows a ‘high risk’ of Down Syndrome, this is not a diagnosis, only a risk of Down Syndrome. Would you terminate before getting a definitive diagnosis from a test like amniocentesis?

- Yes
- No, I would not terminate a pregnancy
- No, I would want a definitive diagnosis through a test like amniocentesis
- No, not for Down Syndrome but I would for other fetal anomalies. Please list them below.

I would only terminate a pregnancy after a definitive diagnostic test like amniocentesis came back positive indicating that my baby was affected with which of the following?

- Anencephaly (a neural tube defect that causes abnormal development of the brain)
- Edwards Syndrome (Trisomy 18)
- Down Syndrome (Trisomy 21)
- Spina Bifida (a neural tube defect which causes incomplete development of the spinal cord)
- I would not terminate a pregnancy

The next section is about the Non-Invasive Prenatal Tests (NIPT).

Please complete the following questions. Tick one.

Have you ever heard of non-invasive prenatal tests?

- Yes
- No
- Unsure

Can you name any non-invasive prenatal tests?

What do you think non-invasive prenatal tests cost?

- €0- €100
- €101- €200
- €201- €300
- €301- €400
- €401- €500
- Over €500

The next section is about the financial aspects of screening tests for fetal anomalies.

Please complete the following questions. Tick one.

How much would you be willing to pay for screening tests for fetal anomalies?

- €50
- €100
- €150
- €200
- €250
- €500
- Any amount
- Nothing, it should be free

Who do you think should be responsible for paying for screening tests for fetal anomalies?

- HSE
- Hospital
- Woman being tested

When/where do you want to receive information about screening tests for fetal anomalies?

- First clinic visit
- From your GP
- Hospital Website

Do you have any other comments or suggestions regarding screening tests for fetal anomalies?